

WV Developmental Disabilities Council

Meeting Minutes

Erickson Center

January 25, 2005

Members Present: Jerri Stephens, Laura Helems, Jeff Marr, Sandy Haberbosch, Clint Martin, Jennifer Waybright, James Qualls, Jane McCallister, Ronald Dean, John Hunneshagen, Christy Bishop, Kim Farley, Cheryl Vega, Christina Smith, Karen Robinson, Pat Winston, Clarice Hausch, John David Smith, and Pat Moss

Members Absent: Lynn Boyer, Ulissa Dowell, Mary Ann Jenkins, Frank Kirkland, Julie Shelton, Ginny Gattlieb, Jeannie Elkins, Terri Rodighiero, Luann Summers, Craig Curtis, and Mary Ellen Zeppuhar

Staff Present: Steve Wiseman, Linda Higgs, Jim Cremeans, and Betsy Southall

Guests: Bobbie Reynolds

Welcome, Introductions and Announcements:

The meeting was called to order at 9:44 am by Laura Helems.

Members of the Council introduced themselves.

Jennifer Waybright read the Mission Statement of the Council.

Laura reviewed the contents of the Council packet.

Steve reminded Members once again about the importance of timely responses to Betsy about attendance, meals, etc. prior to Council meetings.

Steve announced that the Council has a new 10x10 floor display which has been displayed at several events already and will be used at several upcoming conferences, etc. Feedback has been very positive.

Linda announced that there are packets of information available for dentists who provide services to children and adults with developmental disabilities.

She also said that there are registration forms for the Social Role Valorization (SRV) training coming up on February 14 – 17, 2005. It is based on the philosophy of normalization that has been offered through Program Analysis of Service Systems (P.A.S.S.) Training by the Council for several years. She encouraged Members to attend if possible.

Christina Smith announced that she brought the “Health and Wellth” display so that Council members can review what the ARC of Wood Co. has been doing with their grant. She stated that there is a lot of interest in the project in Wood Co.

Public Comments:

No comments were offered.

New Business:

Laura announced that the Council will need to have 6 new members in July. She has asked Clint Martin, Jeannie Elkins, and Pat Moss to be on the Nominating Committee. Steve and Linda will staff the Committee.

Grant Applications: Jim C. gave an overview of the process that was used to secure and review proposals in response to the Call for Investments that was issued in November. He stated that nine Letters of Intent had been received. After the Technical Assistance meeting and feedback to the Letters of Intent was given in December, the Council actually received four proposals. Two addressed the improvement of school to work programs, and two addressed the study of crisis intervention for children. The proposals were sent to the relevant committees for review and recommendations.

Steve stated that there was a large turnout for the Technical Assistance meeting. He felt that the meeting was beneficial to the attendees.

Education Committee: Jerri gave an overview of the School to Work to proposals. She stated that the proposal received from the Wayne County Schools did not meet the targeted goals. Key elements (such as the need to secure a commitment from local business to help improve the school to work curriculum and program) were not addressed in the proposal.

After its review, the Education Committee recommends the REM, Inc. be funded. The two-phase project included an active business partnership with Wheeling Hospital. It also included a plan for job shadowing and other practical job experiences rather than readiness oriented classroom work. The Committee liked the long term planning of the project with the intent to replicate the approach statewide.

Christina asked if the program was only open to REM clients. Jim stated that it would be open to all students.

Clint stated that the Employment Committee reviewed the REM, Inc. proposal and also recommended it for funding.

Jerri made and Jennifer seconded a motion to fund the REM, Inc. proposal for a school-to-work demonstration project in the amount of \$16,609 for FY 2005.

Motion carried.

Systems Coordination Committee: Cheryl reviewed the grant applications to study crisis intervention services for children with developmental disabilities. One was received from HSRI, Inc. and one from Community Access, Inc. She stated that while both proposals were strong, the Committee recommends the one from Community Access, Inc. for funding.

The committee felt that Community Access already has a good rapport with local businesses and familiarity with key in-State organizations. It demonstrated a good understanding of the unique aspects of the relevant WV systems. The application

showed a great amount of detail and research. The proposed, annualized budget is \$42,000.

Clarice stated that the Community Access proposal would also involve the education system which the Committee felt was a key component to success.

Cheryl made and Sandy seconded a motion to fund the Community Access proposal in the amount of \$42,000.

Motion carried.

[Note: the FY 2005 portion of the budget is \$28,000.]

Other Business

Budget: Steve stated that the Council is running a little under budget for the grant projects. He attributes that to having new grants starting up late in the year. He expects that once those projects are under way, the rate of expenditures will be back on target. Office expenses are at or below projections.

The Council has experienced a budget cut of \$6,183 due to a .8% cut to all Councils at the Federal level. He said that the WV Council is working with NACDD to get an increase to funding to state DD Councils.

Steve discussed a \$9,000 grant from the Department of Education to allow people with children with disabilities, other than developmental disabilities, to attend the Partners In Policymaking (PIP) training. Since this offer was received too late to be able to be used this year, he plans to talk to Dr. Boyer about using the money next year.

Federal Medicaid Issues:

Steve stated that the Council does not only focus on State issues, but also Federal issues. He said that the staff will be keeping members informed on both state and national issues and encouraged them to take proactive steps to advocate for people with developmental disabilities as a whole.

Laura cautioned Members to sign petitions (online or written) as individuals, not as a representatives of the Council. Issues supported by the Council must be voted on and officially approved by the Executive Committee or the Council as a whole.

Steve stated that the DD Act will be revised in the next year. He has been working on a workgroup with members of other states to try to help clean up the Act.

Steve gave an overview of some of the Federal Medicaid issues. He stated that there was a request being sent to President Bush asking him not to cap Medicaid. He encouraged Members to become aware of federal issues and take action as individuals as they see fit.

Laura suggested that Members pick up the contact sheet with the names, numbers and addresses of elected officials as well as appropriate letter etiquette.

Steve reviewed some current issues involving WV version of MiCASSA.

Approval of the October 26, 2004 Minutes:

Jennifer made and James seconded a motion to accept the Minutes as written.

Motion Carried.

Updates on Council Activities and Initiatives:

Jim C. gave an overview of the WV Direct Support Professionals Skills Certificate Program (DSP) Initiative. The project is in its second year. One of the end goals of the training is to establish a credential/certificate for direct support personnel that does not currently exist in WV. He stated that they expect to initiate a pilot project beginning in April.

Steve stated that Jeanne Grubb and Kevin Smith are also included on the Direct Support taskforce. He said another goal of the project is to recruit, train and maintain quality individuals in the Direct Support workforce.

Christina asked if the training was going to be free or if individuals would pay for it. Jim C. stated that the pilot project would be free and individuals would only have to have access to the internet. He said the taskforce feels that workers should not have to pay even after the project leaves the pilot stage.

Clarice stated that there is a similar program in NJ, and it is linked into the vocational schools through a CNA program. Steve pointed out that the program is not meant to train individuals in the medical field.

Jerri stated that she felt that career guidance counselors in schools are not aware of many of the disability career paths. Counselors do not encourage students who would be good at these careers to pursue them. A discussion ensued.

Upcoming Trainings

Laura announced that there is a list of upcoming events in the packets that might be of interest to Members.

Steve announced that he and Jan are working on a Self Determination conference and hope to hold it during the last week in June. He said that 2 people from national center on Self-Determination who will speak in 4 different locations throughout the state.

Linda said that the work group is making progress on the Trusts, Wills and Guardianship. She is working on finding someone in WV who can provide pertinent information on the existing laws and regulations in WV. She does not want anyone who will be trying to “sell” a product.

On The Outside

Steve said that they are trying to get the *On the Outside* project back up and running in the school systems.

Steve showed a video tape of an interview he gave regarding Echo McCallister who was featured in the *On The Outside* book. The interview was on *Highlights* with Dick Calloway. Steve was invited to participate in

the interview by Kelly Burns from Museum in the Community. Echo's work is currently being shown through National Art Exhibitions of the Mentally Ill. Echo's work is touring nationally, and the exhibit should open in WV in September of 2005. Steve also helped write an article concerning Echo for the upcoming issue of the "Advocate" newsletter of the Autism Society of America.

MR/DD Waiver Issues

Steve said that the MR/DD Waiver is still the best source of support for people with DD. He stated, however, that there are some changes that have been taking place that could drastically affect the lives of those served, those who should be served but may not be, and their families.

The Council was informed previously that there were going to be no substantive changes in the MR/DD Waiver Manual that was being developed. Upon review of the draft of that Manual, Council staff felt that there were substantive changes to several policies and practices which could have adverse effects on people. Steve, on behalf of the Council sent a memorandum to the Commissioner of DHHR's Bureau of Medical Services (BMS) in which he pointed out several of those concerns as well as to ask for clarification on items that were unclear. Nancy Atkins, Commissioner of the BMS, sent a letter of response. A memorandum was produced that combined both the Council's concerns and questions and the responses from BMS. Steve stated that he was not fully satisfied with the responses. A copy of that correspondence was included in Council Members' packets.

Pat W. indicated that there are approximately 3700 individuals who are served by this Waiver. She stated that BMS acknowledged that they did not get adequate public comment on the new Waiver Manuals (both the MR/DD Waiver and the Aged & Disabled Waiver).

She stated that the Bureau is preparing an application to the Federal Centers for Medicare & Medicaid Services (CMS) to request a five year renewal of the MR/DD Waiver. She stated that the Bureau (through its independent reviewer, the Lewin Group) has held focus forums and has received a great deal of public comment from the advocacy community. She stated that there would not be many changes in the first year (which starts July 1, 2005) although the Bureau has received several comments regarding what people

want. She said more substantial changes would have to be phased in over the other four years. She stated that she foresees a three or four year plan in this regard.

Pat W. stated that the Waiver renewal (including the Manual) will be available for comment around March 1, 2005. BMS intends to post it on the BMS and OBHS websites. She said that individuals would not need a pass code to get into the website. In the meantime, Members could call her at 558-0179 to get a code if they wanted.

Laura began a discussion regarding the mandatory 90 day wait for services once a person is put on the program. Pat W. said that policy was to bring it in line with the A/D Waiver policy. Clarice H. stated that these are two different programs, and the MR/DD Waiver should not be treated the same as the A/D Waiver. A discussion ensued regarding the management of this and emergency situations.

Pat W. said there were certain themes in the feedback received, and she discussed some of the possible courses of action which may be available. The themes in the feedback were:

- Streamlining the eligibility process
- Concern about closure of facility based services
- Reimbursement issues
- Concern about unneeded services
- QMRP (Qualified Mental Retardation Professional) services
- Nursing services (both wanted and unwanted). She stated there are more people coming into the program with fairly significant medical needs. They are working for a balance.
- Obtaining and keeping direct care staff
- Venue for public comment on Waiver program
- IDT (interdisciplinary team) process – Conflicting comments have been received.
- Consumer directed services/education about those services
- Dental/vision services for adults

Laura asked how many individuals were on the wait lists and how many slots remain for each of the two State Waivers. Pat said there were 68 on the

MR/DD Waiver wait list and approximately 600 on the A/D Waiver. She did not have information with her on the number of slots available.

Pat W. stated that the biggest issue she sees with the Waiver restrictions is regarding g-tube feeding. She stated that nurses are not comfortable handing those issues over to unlicensed personnel for fear of losing their own licenses. She said that other states allow unlicensed personnel to handle feeding tubes, and a discussion ensued.

Jennifer stated that she felt that the Waiver should be based on the individual needs of the person because every person is different and has their own needs.

Steve stated that there is a serious issue regarding the increased involvement of nursing in non-nursing aspects of people's lives. There are reports of people without apparent health problems getting nursing plans of care, for example. He said that some of these new regulations do not necessarily make people safer, and they interfere with individuals living their lives. One specific concern is the elimination of the practice of having trained, non-licensed individuals administer g-tube feedings. While he knows of people who have been injured and died as a result of improper oral feeding, he had never heard of a person being injured as a result of g-tube feeding.

Karen Robinson discussed the fact that her daughter has been denied access to the MR/DD Waiver. Steve stated that while we are dealing with the MR/DD Waiver, there are thousands of individuals with developmental disabilities who need supports but who currently do not qualify for the MR/DD Waiver. There are no programs that provide the level of support many of them need. This is an important area of our advocacy work.

Other DD Related Issues

Steve stated that the Commissioner of Behavioral Health had written in a report that funding for the Family Support Program and Supported Employment services and another initiative for people with developmental disabilities within the Division of Developmental Disabilities were being eliminated in Governor Wise's budget plan for FY 2006. There was no new information on this to share. We will monitor Governor Manchin's budget in this regard.

Announcements

Steve announced a national conference titled, The Alliance for Full Participation, will be held in Washington, DC in the fall. He anticipated the Council would want to send a group of its Members to participate in the conference. More information on the conference is available at:
www.allianceforfullparticipation.org.

Laura reminded individuals to complete and return their evaluation forms.

Adjournment

Cheryl made and James seconded a motion to adjourn

Motion carried.

The meeting was adjourned at 2:35 p.m.

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